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ABSTRACT

This paper discusses a study that investigated the management of Tourette Syndrome (TS), particularly how self-reflection and instruction affects the frequency of TS behaviors. The study included 3 girls and 24 boys (ages 7-17) with TS from Victoria and New South Wales, Australia. When students were asked to indicate their general self-image and their self-image when experiencing tics, the majority of students indicated their general feelings of self-worth declined from good or above to just under two-thirds rating their feelings as either low or good/low during tic episodes. Most respondents described their initial feelings about life with TS as negative, but overall predications of life in the future are more positive. Twelve of the students reported they felt they were treated the same as others by teachers and other students. Of the 15 students who said they were treated differently at school, many commented on their advantaged treatment by teachers. Seventeen students reported various effects that TS had on learning, including reduced concentration and obsessive thoughts. Self-management tips identified by students included covering up their tics, thinking about them, and disguising the tics. Factors contributing to student and parent satisfaction with teachers included regular three-way communication. (Contains 16 references.) (CR)

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Managing Diversity: Reflections of Tourette Syndrome Sufferers

Paper for the Second National Conference on Reconciliation, Multiculturalism, Immigration and Human Rights, 2001.

Dr. Jeni Wilson and Bradley Shrimpton

Abstract

Tourette Syndrome (TS) is a debilitating neurological disorder characterised by diversity: diversity of symptoms, diversity in severity and diversity of responses by teachers, families and individual sufferers. The impact of people's responses to involuntary vocal and motor tics of TS can be devastating for sufferers and their families.

TS is not discriminatory, it can occur across all races and socio-economic groups (Wodrich, 1998). Tourette Syndrome is not well diagnosed, therefore estimates of suffers vary enormously. Despite the diversity of the syndrome, it is common that children with TS experience personal distress, reduced self-esteem, social problems (Stefl and Milton, 1985) and school failure (Wodrich, 1998). Most of these children are at risk of becoming, or being classified as learning disabled (Jones & Johnson, 1992).

This paper will present data from a large Victorian and NSW qualitative study on Tourette Syndrome. The focus will be on raising public awareness about the range of symptoms, and the diversity of approaches used by children, families and their teachers for managing TS. The results raise interesting questions and challenges about what is 'normal' and socially acceptable behavior, the rights of TS students, and the impact of schooling on the self esteem and success of students. Strategies used by participants in this study are presented.

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Introduction

The complexities and feelings of Tourette Syndrome (TS) sufferers are not well known by teachers or medical practitioners. Even amongst those with TS, a sense of secrecy and subsequent isolation often exists. It is common for families not to tell their extended family, friends and teachers about TS. While there are a number of reasons for this, fear of responses is a significant one. The desire to be 'normal' and to be treated as 'normal' is often important for students with TS and their families. Ironically, there are negative consequences of secrecy. Rather than protect people from the consequences, these are often exacerbated because of misunderstandings and lack of adequate support. At a general level poor public understanding is maintained. At a personal level, ignorance and limited knowledge can prevent students from receiving fair treatment at school, it can impact upon self esteem and the educational success of students.

There is little written about TS. The literature available is generally limited to explanations of symptoms, possible medical treatments or educational difficulties for TS students. Management of TS is rarely discussed and this is reflected in the feelings of helplessness reported by some families and appeals for assistance by many teachers. Some generalisations about teaching approaches have been suggested in the literature but many seem unworkable in modern Australian classrooms. For example, a suggestion to reduce noise, team tasks and exciting activities may be desirable to reduce stress and tics, but could be detrimental to motivation, sustained engagement and the development of many important skills. Some suggestions also fail to consider the diversity of individual needs of TS students.

This paper aims to increase public awareness by drawing upon the voices of children with TS, their parents and teachers. They reveal their feelings about TS, their perceived treatment by others, effects on learning and management strategies.

What is Tourette Syndrome?

Tourette Syndrome (TS) is a neurological disorder characterised by multiple, involuntary, and repetitive motor and vocal tics. Other symptoms can include repeating their own or other's words, or undesirable words. The latter is often cruelly sensationalised in the media. ADHD and Obsessive Compulsive Disorders are often associated with Tourette Syndrome and other medical problems can co-exist. Tourette Syndrome was once thought to be a psychiatric condition, but it is now known to be is a neurological disorder. It is caused by a chemical abnormality that disrupts messages between nerve cells in parts of the brain. The symptoms are generally worse in the adolescent years. These wax and wane but TS cannot be outgrown.

This is a physical, not a psychological disorder with varying levels of severity. Tics release a build up of tension in a child's body but can also cause pain when they are severe. The complexity of this syndrome

sometimes raises doubt in the minds of teachers and the public about the involuntary nature of the condition.

The prevalence of TS is difficult to determine because of poor knowledge and misdiagnosis of the condition. It is common for sufferers to be repeatedly misdiagnosed and to eventually find out about their condition through sources other than medical practitioners. Estimated figures vary considerable from suggesting 1 in 2,500 (Carroll, Geffen, Comerford, Bailey and Morison, 2000) may suffer from this condition, to as many as 1 in 200 (Juan, 2001). Jones and Johnson (1992) have claimed that among special needs populations, as many as 1 in 4 children have been reported with TS. The figure quoted for boys is usually about four times as for girls.

What are some of the Implications for Tourette Syndrome Sufferers?
Tourette Syndrome is not well understood. It is frequently stated in the literature that children with TS represent the normal range of levels of intelligence, although some sources state that children with TS have average or above average intelligence (Carroll, Geffen, Comerford, Bailey and Morison, 2000). Despite this many children with TS receive unsatisfactory education. Children with Tourettes do not have diminished intellectual capabilities but without proper intervention and appropriate learning experiences they can be at educational risk.

Children with TS are sometimes treated with rejection (Parker, 1985), ridicule (Lerer, 1987) and suspicion. Adults may believe that children are just "doing it to be naughty". The possibility of tic control is debatable, but generally tics should be viewed as involuntary. The results of this study confirm earlier claims that while some tics may be temporarily suppressed, they must be eventually released as suppression can be painful. Other people's negative responses to tics can also cause extreme anxiety, which in turn can increase tics and can cause self-doubt.

TS can make many simple and routine activities like reading and writing more difficult. This is especially true if children are trying to suppress tics. Tic suppression requires much energy; therefore it is difficult to concentrate on classroom tasks. It is for these reasons that it is not advisable to tell children to suppress tics. But regardless of teacher acceptance of tics, students may try to suppress tics anyway because of the concern for unwanted reactions of peers and others. For example, Mason (8 yrs) explained: "People don't like to look at it."

Frustration is another problem for children with TS. This disorder causes excessive movement, interruptions, tension and pain from persistent jerky movements of tics. Frequent ticcing is very disruptive for learners and physically getting their work done can be overwhelming. For example, Ron (12 yrs) finds anything he has to do with his hands awkward. A few students (usually from private schools) in our study have been provided an aid to write for them.

Task avoidance is another real issue for anyone finding tasks difficult. Add to this self-consciousness about unpredictable behaviour and noisy classroom situations which can aggravate tics, and school can become a daunting place. Some planning and adjustments to classroom requirements could make the difference between motivation and feelings of failure (see discussion).

The range of symptoms of TS and therefore the range of needs is diverse. Not surprisingly, Burd, Kauffman, Kerbeshian (1992) found that the most successful learning programs were able to accommodate students' individual needs. Case study material is rare but is desperately needed for a better insight into the educational needs and appropriate care of individuals. The case study approach for this research is in its first year.

Research Overview

This research aimed to investigate the management of TS, particularly how self-reflection and instruction affects the frequency of TS behaviors but the results have been broader in scope. This research has explored the complexity of the syndrome, management and linked educational needs. This paper will discuss case study data about students with TS (aged 7-17 years). Although the data collection has not been completed, 27 student questionnaires, 8 student interviews, 16 parent interviews and 4 teacher questionnaires have been completed making it a large study of this type in Australia. Further case study data collection is planned. This paper represents analysed responses from Victoria and NSW (3 girls and 24 boys).

Background Information

Sixteen students are currently on medication and 18 experience or have experienced side effects. For example, tiredness, weight gain, anxiousness and phobias. Although the tic behavior of students varies for each child and over time, the frequency for the majority of children in this study was categorised as mainly high (per minute or hour). The students reported a wide range of behaviors that are ever changing, these included: Twitching and jerky body movements (N=15), Vocals e.g. clicking noises/throat clearing (N=14), head nodding/jerking neck (N=12), blinking (N=11), sniffing (N=5), teeth grinding (N=3). Other behaviors included: finger licking, squatting, cracking toes and fingers, jaw dropping, grimaces, chewing, and ankle rolling.

It is noted that parents discussed a broader range of tics when reporting about symptoms over time, and although no students reported anger outbursts, these were reported by parents. Other medical problems (such as ADHD and OCD) were not the focus of this investigation but many of the students involved in this study did have a range of medical problems.

Findings

A large amount of data has been collected. The following aspects of the data are presented in this paper:

1. Feelings about Themselves and TS
2. Treatment by Others
3. Effects on Learning
4. Self-Management of Tics
5. Management of Tics by Parents
6. Management of Tics by Teachers

1. Feelings about Themselves and TS

To explore the relationship between positive and negative self perceptions and tic behavior, students were asked to indicate on a scale their general self-image and their self-image when experiencing tics. Table 1 and 2 show that for a majority of students general feelings of self worth declined from 'good' or above (N= 18/27), to just under two thirds rating their feelings as either low, or good/low during tic episodes (N= 17/27).

Table 1. Feelings about Themselves Generally

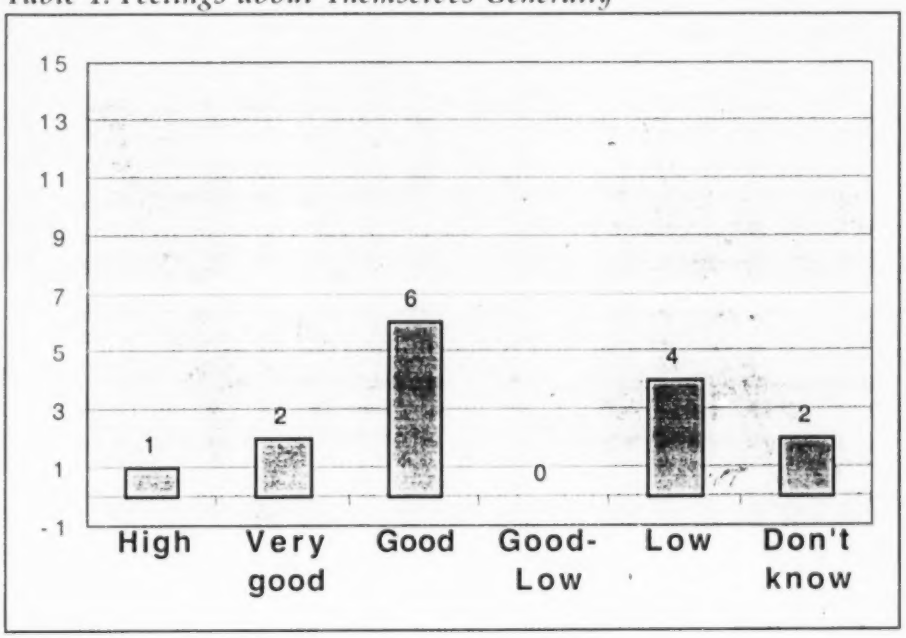

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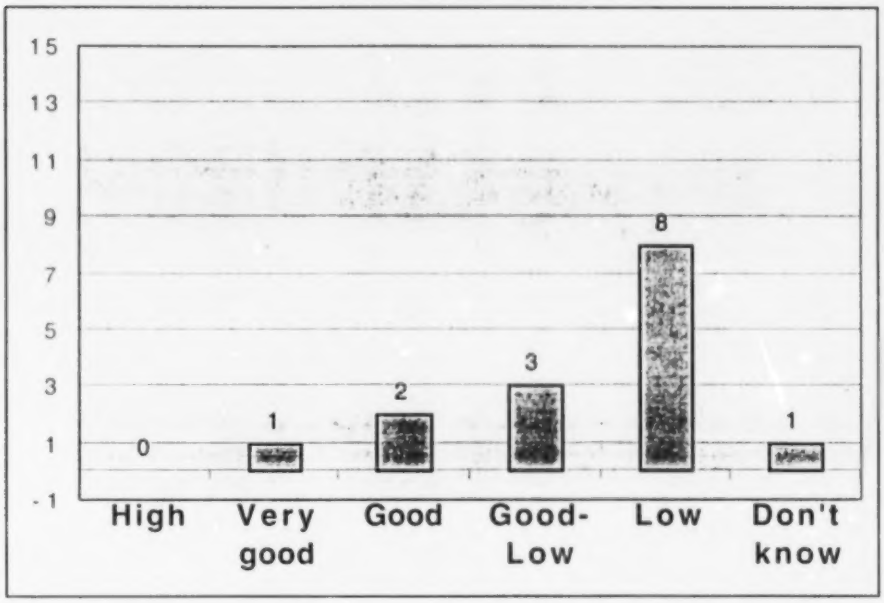
Table 2. Feelings about Themselves with Tics



Many of the student responses related to their feelings about having Tourettes reveal a progressive shift over time (see Table 3). This is consistent with what might be expected when children and their families learn to cope with a chronic illness (see Eiser, 1993). Most respondents have described their initial feelings about life with TS as negative, but overall predictions of life in the future are more positive. In some instances the need to accept and live with their condition was expressed, for example Ron (12 yrs) said: "No fairies going to wave a magic wand and make it better". In some cases though, children believe that their condition will go away and even though this is not true, parents knowingly do not dispute this hope.

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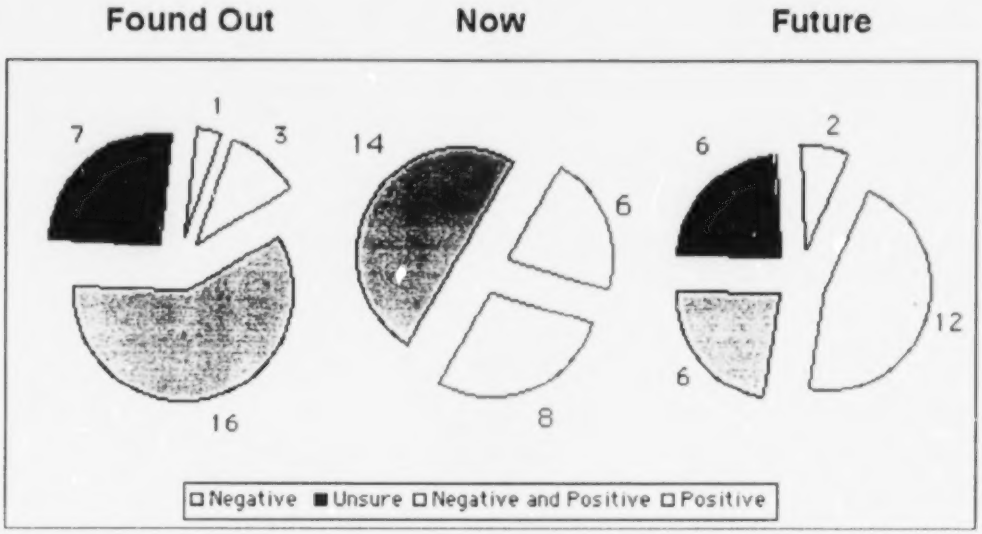
Table 3. Feelings about TS



The following two quotes demonstrate the range of emotions uncovered in the research.

> 'I was devastated [when I found out I had TS]. I thought I was going to be a normal boy. But I'm not. My life is awful. I feel like they [tics] are controlling me and that I look stupid. I feel like I'm missing out on a lot of things because of my tics. I will feel a lot better if my tics go. If they don't I will learn to put up with them'. *(Neil, 9yrs)*

> 'I felt like I was the odd one out. My friends did things like sport and I really liked it too, but when I got excited I ticked a lot and didn't concentrate properly. [But now] it's great! I mean I'm still the same person. I have no idea [of what my life will be like in the future] it's going to be whatever I make of it. *(Amy, 15 yrs)*

Children's responses to TS were often different to parents who consistently reported being relieved when first diagnosed. This response is not because the parents want such a condition, but rather that the known is preferable to the on-going medical scrutiny. Prior to diagnosis most parents (almost without exception) have endured many misdiagnoses and sometimes negative insinuations about their parenting by doctors and others.

A range of other parent responses were also common, for example, fear and worry for their child's future, anger and guilt about not pursuing their. One father cried for three months when he found out his son had Tourettes. Many parents asked questions such as: "Why us? Why me? I've been a good parent." Resentment and disapointment often follows when

parents cannot get support they need. But as one of Rick's (13 yrs) parents stated in an interview: "You find the strength somewhere and put priority where it's needed most. You try to help you child have a happy life." This response characterises the burden often felt by having a child with TS and also the commitment parents put into this often taxing responsibility. This 'strength' may also help account for the changing perceptions of children over time.

A feeling of wanting to get on with their lives as best as possible after finding out about TS pervades parent data. Although many parents say that they just live 'day to day' and try not to worry too much about the future, the enormity of fears underlies many parents responses to other questions, for example: "What happens to these kids when they get a car?"

Nevertheless, both children and parents seem to eventually accept (we cannot say like) the condition and the broad implications it has for their lives. But parents strongly reject and resent the negative and unsympathetic responses of others.

2. Treatment by Others

Twelve out of the twenty-seven students of the study cohort reported they felt they were treated the same as others by either teachers and/or fellow students in class. Of the group (fifteen of twenty-seven) who said they were treated differently at school, these responses were not all negative. Many students commented on their advantaged treatment by teachers. For example: "My teacher treats me like an angel and manages my Tourettes really well. The other students try to be understanding as my teacher has told them all about TS. "(Neil, 9 yrs) and "No, I get treated like everybody else in my class, but I used to get treated differently by doing less amount of work, and being let off easier." (Howard, 14 yrs)

It is noted that while such teacher actions may be intended to support students and that students may accept them as favorable, in the long term such actions may not be of benefit to learning. Requiring less work and treating students differently may reinforce or create feelings of inadequacy or disadvantage them academically.

The positive data reported by some students about school treatment is surprising and inconsistent with data collected from parents and teachers. There are several reasons why the authors believe that students reported no difference or more favourable treatment. These partly relate to methodological problems of questionnaires. We believe that some responses to the question: Do you believe you are treated differently in class? were interpreted as: Should you be treated differently in class? Another explanation for this unexpected response could be that students desire to be treated like everyone else and therefore respond in this way. Alternatively they may be unaware of the difference in treatment or do not want to say that they are treated differently. For example, one student reported he wasn't treated differently yet his parent and teachers both reported that he sat on a table alone to increase his concentration while

everyone else sat in groups. Students have commented on current classroom experiences while parents have reported on current and past experiences.

Incompleteness of data can be a problem in studies using children's self-reporting nevertheless a study of this kind necessitates self-reporting. Triangulation has been used to increase the trustworthiness of the data.

In contrast to favorable school experiences, some comments revealed disturbing school experiences. John (14 yrs) reported unrelenting harassment: "I used to get asked why I blink all the time and everyone used to get angry at me because I couldn't help looking at them and I always get harassed." And Sam reported exclusion by some kids: "They think of me as a freak of nature. They call me a freak. These kids think I am not one of them!' and Lyle (9 yrs) says he feels like he's in prison when he is at school.

At one stage Amy's mum withdrew her from schools and taught her at home (a choice some parents TS sufferers feel compelled to make). Despite the fact that Amy has had many years of negative schooling experiences she has come to accept her own behavior as 'normal', she compares her behavior to her peers: 'I do silly things, but my friends don't have TS and they do silly things too.' (Amy, 15yrs)

Students more often reported that they had been treated less favourably by other people (outside of the classroom and school) because of their TS. Such comments may suggest that classrooms provide them a sense of security. What happens in class as compared with what happens in the playground or elsewhere, may be more positive because of teacher 'protection'.

Students may also be more self-conscious in other environments such as home, in public and the schoolyard. Another possible explanation for this data is that concern by family members may be more intense than concern shown at school, for example: 'Mum and Dad are always worried about me when I don't want them to be.' (Jess, 14yrs)

3. Effects on Learning

Student thoughts about the impact of living with Tourette Syndrome on their learning provide clear anecdotal evidence of the disruptive nature of Tourettes. Seventeen out of 27 respondents reported various effects that TS reduced concentration, created obsessive thoughts that inhibited class participation, affected their friendships and caused vocals and twitches that disrupted collaborative learning and learning in general. For example, both Mason and Neil are high achievers, but they discuss different problems. "Tourettes stops me doing things.' When I want to do something, something comes up in my mind saying don't do it – it's really annoying."(Mason 8 yrs) and "Yes, it affects my concentration as I make noises while the teacher is talking and miss some information. It really

affects my friendships, as people don't really understand about my tics." (Neil 9 yrs)

Some students reported that TS had not effected their learning. However, parents indicated that their children's perceptions were not always accurate, for example, a parent commented that although their child said it hadn't affected his learning their 11 year old son had yet to progress beyond basic reading and writing abilities. Again parents do not openly challenge children's misconceptions for fear of dampening their positiveness or creating further educational problems.

The two students who responded to this question as 'unsure' did not have parent comments to verify or deny their claim. It is possible that these students may be unaware of the disruption Tourette has on their learning as discussed earlier.

4. Self-Management of Tics

Students were asked to report on strategies that they used to stop or cover up their tics. The range of responses is another example of the uniqueness of TS characteristics and demonstrates the differences in ways individuals respond. Tic suppression is often advised by medical practitioners, parents and teachers to disguise tics. The underlying message for TS sufferers is that the behavior is not acceptable, it is wrong and it is not normal.

Two thirds of the students in this study indicated that they try to cover up their tics, some have stopped trying. Tic suppression is most likely to occur in public situations rather than at home. Many students go to great lengths to 'disguise' their tics to avoid ridicule and embarrassment but expressed a difficulty in holding back or covering up their tics. For example: "I try to cover my mouth to muffle my tics - [illegible] I have trouble trying to stop them.' (Neil, 9 yrs) and 'All I really do is try to make it as less noticeable [as] I can. If I ever get seen doing tics then I just look away or pretend I was doing something else." (Howard, 14 yrs). Again Amy provides an alternative response to most: "No - I just let them happen, because if I hold them back, they will build up, then start like an explosion!" A number of students described the inevitable result of tic suppression in a similar way.

In this cohort the most successful strategy used to cover up or stop tics was thinking about them (N=7) but this was also reported as one of the least successful strategies for three children. Holding back was named as a most successful strategy for two students but five students included it as one of their least successful strategies.

Another successful strategy was categorised as 'hide and disguise'. This is where students reported pretending they were doing something else, for example a mouth opening might be 'turned into' yawning, or a flinging arm might be made to look like an intentional wave. Some students such as Chris reported covering up their tics, for example: 'Putting my head

down and covering my face." Other examples of strategies and supporting quotes are given below in Table 4.

Table 4. Most/least successful ways to stop/cover up tics

Most	Least
Thinking 7 *'Try to keep you mind off it by doing or thinking of something different.' (Howard, 14yrs)*	**Thinking** 3 *'Sometimes if I think about them it makes them worse.' (Sebastian,10 yrs)*
Hide and Disguise 5	**Hide and Disguise** 1
Hold Back 2	**Hold Back** 5 *'To try to suppress them.' (Neil, 9yrs)*
Nothing Works 1	**Nothing Works** 1
Other: 4 *'Resting'*	**Other**: 6 *'Letting it happen'*

There is no evidence to suggest that people with TS take any pleasure in tics, that they do this on purpose or that they are deliberately used to attract attention. Quite the contrary, the findings indicate that tics cause children to be anxious, angry and distressed over their unpredictable behavior. Although they don't tic by choice, a few of our older students and some with mild TS have accepted their ticcing.

It appears that individual students have tried a range of strategies. The success of the strategies varies across students but can also vary for individuals according to circumstances. For example, thinking about tics might work well for some students in some situations but not in others. Sam says to himself (out loud) "Stop, Shut up and the 'f' word" but none of them help. He says he still does it anyway "because it lets the anger out."

Out of 27 students who responded to the question: Do you ever talk to yourself about your tics? Sixteen indicated they hadn't while 11 said they had utilised self-talk. Several respondents reported using inner comments aimed at self-control such as: "Don't do it" and "Concentrate." Other examples of self-talk included attempts to reduce anxiety: "Calm down," "Be quiet," or to minimise the possibility of embarrassment, "try to stop it because there's a lot of people around me and I don't want to be noticed doing my twitches." Respondents reported mixed opinions about the effectiveness of this self-management approach, with several students noting "it helps reduce tics", but for others self-talk worked rarely or not at all.

In an evaluation of behavioral treatments for TS, Peterson and Azrin (1992) found that a range of procedures were effective for at least one of their subjects. They found that self-monitoring resulted in the largest reduction in tics in children but they did not note any ramifications for learning. They concluded by recommending self-monitoring as the initial behavioral approach to tic control. Their study was small and ours is inconclusive therefore this requires further research.

5. Management by Parents

Most parents reported that they did not know what tics were displayed at school or if teachers are using any particular management techniques. In some ways this seems surprising because of the energy parents expend on dealing with TS at school.

There are several possible explanations for this lack of knowledge of ticcing and management at school.

1. Parents not interested in what happens at school
2. Parents are reluctant to approach teachers
3. Parents and or children do not wish to attract any more attention
4. Parents do not wish to continually raise the issue with their own children
5. Teachers are not communicating with parents

The first possible explanation can be excluded. All parents in this study (who have informed teachers about their child's TS) spent and continue to spend considerable hours raising teacher awareness about TS. Parents in this research have gone to great lengths to collect information, for example from internet searches and TS Associations and other parents. If the school is told of the child's TS condition, the parents have taken nearly all the responsibility to educate teachers about the condition by providing written information, videos, arranging guest speakers etc.

The most likely explanations relate to parents' own feelings of anxiousness about discussing TS with teachers and fear of the consequences for their own children. For example, one parent shared her reluctance about approaching schools: "The teachers he likes speak highly of him but teachers he doesn't like think 'Oh here comes that mother". Another parent was confronted with a teacher's comment: "Isn't there a pill you can give her!' This was offensive to the parents because the child had suffered many side effects of medication for years and was trying to cope without medication.

In most cases teachers did not approach parents about what was happening at school unless there were major problems. This means that parents are largely unaware of teachers concerns vice versa. Where teachers have expressed a willingness/ interest to discuss TS, parents have always been grateful. A feeling of satisfaction by children, parents and teachers is generally the result.

At home a range of management strategies are used by parents, for example: relaxation techniques such as deep breathing, Reiki and massage, 'stop 'n' think' and psychological support. Parents have made comments about the ineffectiveness of suggested techniques by doctors. For example, one doctor said "When he's good give him a hug and when he's bad give him a smack – it's that simple." But the parent commented that her son wasn't bad – he just did some things that seemed strange. Not surprisingly many strategies have limited effectiveness because of the involuntary nature of this condition. What is surprising is that many of the management strategies had not been planned but are used as 'hope for the best' crisis control strategies as needed. This reveals the uncertainty of parents and lack of support for the condition.

Many parents avoid public situations. One parent commented that "It's very easy to closet these kids because you want to protect them." To avoid embarrassment was another reason families for keeping to themselves. When in public, substitution or 'cover ups' have been suggested by some parents to their children. None of the parents in this study have asked children to stop ticcing at home after they have had a diagnosis. For example, one parent said "In time [if he can stop his tics] well and good but if not, that's Jed and so be it!"

6. Management by Teachers

The range of responses by teachers about their management strategies was large. Some had not discussed management with children or parents at all (in low level TS cases). Some techniques suggested deep breathing and relaxing for children when they are distressed or 'badly' behaved. Others had devised behavioral intervention strategies such as time out. Another strategy sometimes used was for students to sit at the back of the room. This was used to reduce attention on tics or to increase chances of concentrating. Unfortunately these good intentions were not necessarily communicated to parents and children and as a result were sometimes considered undesirable. Parents very rarely communicated their concerns or unhappiness about teacher's strategy choices.

In one classroom where the child and parent are extremely happy, the teacher reported that: "I don't treat him differently than anyone else." In her room the teacher works hard at creating a caring, 'family like' environment where everyone is treated with dignity.

In general the following factors contribute to student and parent satisfaction:

- Regular three way communication
- Increased self esteem of students
- Consistent rules that are "livable for everybody" (teacher)
- Clear expectations
- Individual needs are accounted for

- Recognition of everyone's rights
- Time out plans

It is clear from the data collected that the teachers (like parents) need advice about classroom strategies and support in their management of students with TS. Most teachers would have no previous experience with a child with TS and therefore their management techniques may be haphazard and unplanned.

Discussion

The knowledge and skills required of teachers working with children with other chronic medical problems also apply to helping children with TS. It is always important to first consider the abilities and needs of the children involved and to seek parental feedback. Children with TS can face physical, social, emotional, psychological and other medical problems that can be ignored by schools. These dimensions provide a framework for teacher decision making. The assistance of other specialists, such as a psychologist, teaching aid or support groups can be advantageous.

Although the data analysis of parent and teacher responses has not been completed, it is quite clear that what teachers do and say makes a difference to children in their care. The teacher has an enormous impact on children through modelling and monitoring student responses. It is worth remembering that children with TS get frustrated and embarrassed about their involuntary actions and noises as much (or more) than others do. Pointing out tics is counterproductive; the stress this may cause can heighten the symptoms and negatively affect self-esteem and desire to learn.

Other disorders sometimes experienced by students with TS, for example OCD and ADHD cause bigger challenges to behaviour and learning. These disorders cause a wide range of difficulties, such as attention and impulse control difficulty, therefore each student and task expectations must be considered individually. Being flexible and adjusting expectations are most likely necessities when teaching students with TS. For example, some students are exhausted when they get home from school and they cannot complete homework. More than one student reported going to bed virtually when they got home from school and sleeping until it was time to go to school the next morning.

A multi-faceted and integrated approach to planning learning for students with TS has been developed from this initial research. It is recommended that due attention is given to the following major dimensions: Physical, Social, Psychological and Medical as a starting point for planning. These dimensions are not mutually exclusive. Within each dimension, the teacher, parent and student can identify individual needs and act together to create classroom conditions that enhance learning (see Wilson and Shrimpton, 2001). Uncovering the shroud of TS secrecy that often pervails

is an important starting point for open communication and educational success.

Conclusion

Australian qualitative research on the learning implications of Tourette Syndrome is rare. Although this research is not completed, nearly 60 people have been involved in this research. It provides rich, thought provoking data about students as individual people with individual abilities, rights and needs. The research has investigated the management of TS behaviors and in particular the diverse impact on the lives of these children and their families.

In the typical lives of TS sufferers, it is common for them to be:

- misdiagnosed
- considered a behavior problem
- embarrassed and frustrated by their condition
- lacking confidence and to suffer years of self doubt
- isolated from friends and family
- disbelieved about their lack of ticcing control
- put off sport because of comments about their lack of apparent coordination
- discouraged from academic pursuits

For fear of the consequences of ticcing many people with TS use techniques to try to look 'normal'. Unfortunately, this is not normal and does not feel normal for TS sufferers and it can cause further anguish when trying to suppress and disguise tics. When she was younger, Amy (15 yrs) felt that everyone was against her but now Amy has a very positive attitude towards her condition. She doesn't see TS as different: "It's just another label, everyone has a slight problem. It's normal to me."

We can learn a lot from listening to children with Tourettes. Mason (8 yrs) made an insightful comment that no one would ever want their own child to make. He has a long way to go before he gets to Amy's level of acceptance and understanding. Mason said: "If there were two of me and I looked myself in the eye, I'd feel sorry for myself – cause it's just not normal."

The data from this research demonstrates that many children with TS endure unfavorable, unwanted and sometimes extremely unfair treatment by others because of a reluctance to accept and embrace diversity. Educational advancement for children with TS can only be achieved when teachers understand and accept the diversity of TS needs.

A supportive educational environment is crucial to contribute to the future success of children (Parker, 1985 and Lemons and Barber, 1991) so that they can operate as confident, capable and active social beings. It is

essential to promote understanding, open-mindedness and empathy for people with TS and to develop the educational potential of these children who are at risk.

It is hoped that this paper will raise awareness, interest and approaches to this fascinating, multi-faceted disorder. The results of this research raise interesting questions and challenges about what is 'normal' and socially acceptable behavior, the rights of TS students, and the impact of schooling on the self esteem and success of students. The role of the teacher/school and the nature of effective interactions with families deserve further research.

The final words are left to Ron (12 yrs). He says that there is always a wish that someone can make him better but Tourettes, he claims, is not going to stop or effect anything he does- we hope he is right.

> "Now, mostly I don't bother stopping [tics] ....I can put up with it cause no fairies going to wave a wand and it's gone. I feel the same- I don't care I have it. I would just like to be treated the same as everyone else."

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Dedication
To all students who have Tourettes or who are educationally disadvantaged and especially for Madison whose insights can distress but also inspire me.

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